



Working with AIDS Bereavement: A Comprehensive Approach for Mental Health Providers

Peter Goldblum, PhD, MPH and Sarah Erickson, PhD

Prologue: A Personal and Professional Journey

I remember that first time in the early 1980s when I walked into a hospital room as a psychologist to counsel a dying patient with what was then termed “Gay Cancer.” When my colleague, Patrick McGraw, called with the referral, he spoke in a sad tone with a touch of irony in it, “I’ve done all I can do for him medically. This is the time I usually ask the chaplain to go in, but neither Ron nor his lover, Sidney, feel comfortable with a priest or rabbi, so I thought a psychotherapist would do. Anyway, I figured you’d know what to do.”

At first I was flattered, then bewildered; nothing in my psychological training prepared me to make such a visit. As I walked up the steps to the hospital, the words “compassionate care” kept coming to my mind.

When I entered the room, I found a gravely ill man in the hospital bed, his partner standing next to him holding his hand. They were expecting my visit and welcomed me cautiously. Trained by frequent visits from medical consultants, the couple fell into telling me Ron’s medical history. I was glad they did, because it gave me time to think about what I had to offer these men. When a nurse came in to do a brief medical procedure for Ron, I got another reprieve.

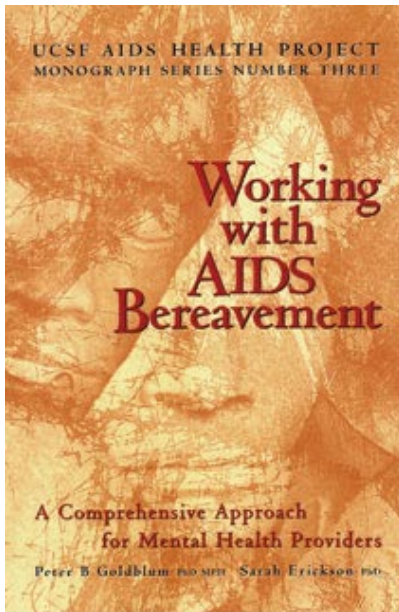
In the hallway with Ron’s partner, Sidney, I asked him how he was doing. Obviously exhausted, he bravely reassured me that he was holding up. I then asked him if there was anything that he wanted to say or

wanted to hear from Ron that wasn’t being said. At first Sidney seemed surprised by the question, but then relief spread over his face. “Well, yes there is,” he said. “Ron and I have been together for fourteen years. We have a beautiful home together and raise prize show dogs. We get along wonderfully. Neither of us is what you would call ‘mushy’; we haven’t had sex in years, and that’s fine with both of us. I know that he loves me and would do anything for me, but neither of us has said that to the other for a long time. I would like to hear him say he loves me and I want to tell him how much I love him, but I feel embarrassed.” I asked if he would like me to help them have that discussion, and he said he would.

Relieved to have a purpose, I returned to the room with Sidney. I told Ron that the reason for my visit was to help him and Sidney say those things they wanted to say to each other before they had to say good-bye. Since no one really understood the disease that he had, no one could really predict the future. Ron broke in at that point and said, “I know that I’m dying. I need to start saying my good-byes.”

Ron started out in a weak and frail voice. “Sidney, I know that I don’t say this as often as I should, but I really want you to know how much I love you and that my only regret about dying is leaving you.” All three of us began to cry, as Sidney proclaimed his unending love. Shortly, I excused myself, gave them my card, and said I would check in over the next few days.

Two days later Sidney called to tell me that Ron had died peacefully. He thanked me and told me that the last two days were the closest of their lives. Again, with a quiver in my voice, I encouraged him to check in with me whenever he needed. I did not hear from Sidney for several months; then he called and came by my office for



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one session. He wept as he described the last days of Ron's life. When I asked Sidney how he was doing now, he said that he was progressing well busy with the house, garden, and dogs. As he was leaving he said, "I just want you to know what a comfort it is for me knowing and having heard from Ron that he loved me. Thank you."

Witnessing Bereavement

I learned many things that day with Ron and Sidney. First, bereavement work begins long before a person experiences a death. Getting respectful, compassionate care from medical providers, having your relationship honored by others, and knowing that you have done a good job caring for a loved one: all of these go a long way toward facilitating the mourning process. Second, at the core of what we as mental health professionals do is compassion. Our ability to be present with our clients and to listen with an open heart will usually guide us to do the right thing. Finally, compassion and knowledge augment and potentiate each other: knowing what we are doing what is expected of us allows us to focus more compassionately on our clients' needs rather than our own insecurities.

Over the years since I met Ron and Sidney, I have watched as AIDS has compelled so many of us to face our mortality: many have died, many more live on infected, and all of us know more profoundly than we did about the temporary nature of life. For those of us who have weathered the losses of the epidemic, the threat of becoming overwhelmed and demoralized is a real danger. As therapists working on the front lines, we run the real risk of falling into what has been termed "empathy fatigue." I know, for I have been there.

I particularly remember the trying times during the final days of my partner Kenny's life. With the help of a wonderful group of colleagues, I found the courage to discuss my situation openly with each of my clients. To my surprise, I received nothing but the kindest support from each, and together, we were able to define a suitable course of action: some went temporarily or permanently to other therapists; others took a break from therapy and returned later. I have never viewed my clients in exactly the same way again.

After Kenny's death, I took a two-year break from doing psychotherapy. In 1989,

I became interested in doing research on AIDS bereavement. A friend of mine who worked for the AIDS hospice program at the San Francisco Visiting Nurse Association referred me to Susan Nolen-Hoeksema, a teacher and researcher at Stanford, who was the principle investigator of a large bereavement study funded by the National Institutes of Health. The suggestion was timely, given Susan's interest in expanding her research to include the AIDS bereaved. Soon, she invited me to join her bereavement research group and work with her then-graduate student Sarah Erickson to develop the AIDS Caregiving and Bereavement Study.

My experience at Stanford opened my eyes to the complexity of the study of bereavement in general. I came to realize the gulf between clinical lore and empirical evidence. Further, I was exposed to two apparently opposing theoretical and research traditions: the more empirically driven stress and coping model and the more theoretically driven psychodynamic model. At times I felt like a fish out of water; surrounded by highly skilled, technologically sophisticated researchers, I often heard disparaging remarks about "soft thinking" clinicians. At other times, I felt that these "egg heads" totally missed the point and were more interested in statistical significance than real life significance. Fortunately, I had an ally in Sarah, who is one of those amazing people who is equally comfortable in both worlds. We spent many hours which usually included enjoying a nice meal and some gossip trying to reconcile these two perspectives. I like to think that we have grappled with these issues in a way that is "tough minded and kind hearted" (a term used to describe the late Congresswoman Barbara Jordan).

Since returning to psychotherapy, I have been privileged to work with many gay men grieving AIDS losses. Some have lost romantic relationships, others grieve the loss of deep friendships. I have come to think of all of these stories as love stories. Each contradicts the homophobic belief that gay men do not form deep emotional attachments. Each has taught me the art of loving: the ways relationships start, how attachments form, and how affection can deepen over time. As with any love story, most include conflicts, some that resolve, some that remain.

True Story One: William and David

This monograph includes three “true stories” to more genuinely reflect the experience of AIDS mourners. The first, below, is an excerpt from a letter sent by William Aull, a nurse at the Rainbow Home in Pennsylvania, to the editor of *On Display*, the newsletter of the AIDS Memorial Quilt. William’s is a common but rarely told story. As health care providers, we often develop deep emotions for our patients; occasionally an especially deep relationship forms.

I, like many other professional caregivers, have had many friends who have died from AIDS too many to count. I did not know David prior to his admission to Rainbow Home, but I grew to know him very quickly and I want to share my experiences as his caregiver and friend. David came to us from a nursing home in another state. . . . He was very angry and I could understand why he felt this way.

David was one of the lucky ones he had tremendous family support. His mom and several of his aunts were nurses and would spend as much time with him as possible. . . . I finally had someone with whom I could discuss opera. I prefer Leontyne Price; David had other favorites. . . He also liked Barbra Streisand and Madonna, so we’d listen to these tapes together while I was performing care.

David longed to get out into the world and see things. He simply wasn’t ready to sit and watch TV all day. We had a lot of work ahead of us. He had minimal use of his legs, but was determined to walk again. We hoped the “cocktails” his new doctor prescribed might be the key to his dream of walking. We worked long and hard on range-of-motion activities. Our duo wasn’t about to give up the ship! David’s legs eventually strengthened to the point where he could walk for short periods of time. Our most joyous day was the day he and I went to Sunday Mass and he was able to get into and out of the car on his own. It was a miracle! . . .

A week after David and I attended Mass, just one week after his great triumph of walking, he took a sudden and unexpected turn for the worse. I was blessed that my co-worker understood how important David had become to me and she set me free to help David through the dying process. Hour by hour his condition worsened and he kept asking me not to leave him. At 2:18

p.m. on January 5, with his head on my right shoulder and his family by his side, listening to Madonna, David went to God. He died with dignity and respect, pain-free, surrounded by those who loved him.

My grief actually started the morning David started to deteriorate. When David died on my shoulder I knew the end had come, but I couldn’t move. I needed that bond to send him to God. I remember laying my head on his chest and sobbing. Then I went about my duties notifying the rest of the staff, calling the priest and gathering his belongings. It was shift change and the woman who replaced me graciously gave me permission to prepare the body for the funeral director. We are family at Rainbow Home and this is one of the ways we help each other cope.

I had to leave before the funeral director arrived because the pain was so great. Besides, I had promised David I would do something if “that time came.” I went to a local bar and all of us there drank a toast to David. It’s months later and I’m still healing. I know it will take a long time. He was very special to me.

As frequently as these special relationships happen, little is written or taught about how to manage them. As wonderful as these relationships are, they can also be confusing given their mixed professional and personal nature. Because these relationships are not widely discussed, they sometimes make other co-workers a bit uneasy and families sometimes feel displaced by their intensity.

On the other hand, too often family and friends of the patient are unaware of the special nature of these relationships and professional caregivers are left out of final ceremonies, their role and their affection left unacknowledged. Fortunately, both William and David had solid support and validation for their friendship. David’s family allowed William to join them before, during, and after David’s death, including helping to make David’s Quilt panel. William also received support from his colleagues, which will hopefully continue throughout his mourning process.

I am grateful to William for so candidly sharing his intimate story. Only as we openly tell stories of the deep bonds that we form with our clients can we begin to understand how to manage and mourn them. Yes, AIDS is both

a nemesis and a teacher. The lessons learned are hard ones, and the losses are great. Each of us who confronts the disease and its losses must find his or her own strength to face its burdens and to find meaning within the struggle.

In the model we present in this monograph, we struggle to combine insights derived from the latest empirical and theoretical work with direct observations taken from our personal experiences and those of our clients. We have worked hard to soften the academic tone without losing too much in the way of precision. We have tried to provide a useful clinical model for the assessment and treatment of AIDS bereavement distress, while acknowledging that there still exist many unanswered questions. We have offered our own synthesis of a large and often contradictory literature on the subject. However, we have noted those areas where there continues to be disagreement or inconsistencies in the literature with the hope that the interested reader will hold these conclusions as tentative and will continue to follow future developments in the field.

—Peter Goldblum, PhD, MPH

Introduction: Overview and Definitions

AIDS mourners, and those who seek to assist them, face an ever-changing landscape of cultural and individual meanings related to the nature and social implications of HIV disease and the losses associated with the epidemic. These meanings profoundly affect an individual's response to loss and the success with which he or she resolves grief. The process of finding meaning in AIDS grief is facilitated by a well-grounded, comprehensive view of AIDS bereavement, a perspective that takes into account the historical and cultural contexts of AIDS bereavement and the psychological processes affecting AIDS mourning and grief. This monograph proposes such a perspective: the Integrative Model of AIDS Bereavement.

Contents

Chapter One lays the groundwork by discussing the historical, cultural, philosophical, and psychological contexts of mourning and specifically AIDS bereave-

ment. Chapters Two and Three synthesize this material, borrowing from this library of theory the elements that comprise the Integrative Model, which will aid providers to assess and treat clients who need help navigating their mourning process.

The Integrative Model is based on empirical research, theory, and clinical observation related to both AIDS and general bereavement. This model is designed to help clinicians evaluate the type and level of bereavement distress experienced by an AIDS mourner, distinguish between uncomplicated and complicated grief, and determine whether a psychiatric disorder co-exists with grief. As part of this assessment, the monograph presents a procedure for evaluating risk factors for AIDS bereavement distress. This procedure is grounded in the latest findings in the AIDS and general bereavement literature.

The monograph then describes a range of bereavement activities and interventions and a method for matching AIDS mourners with appropriate bereavement activities on the basis of type and level of bereavement distress. Finally, the monograph proposes a psychotherapeutic approach Integrative AIDS Bereavement Therapy that combines aspects of both psychodynamic and cognitive behavioral therapy and is enhanced by recent developments specifically designed to assist AIDS mourners in preventing complicated grief.

Terminology

In a volume that seeks to synthesize the broad bereavement literature, the dilemma of selecting appropriate terminology is unavoidable. Even as the field explodes with new and sophisticated research on both bereavement in general and AIDS bereavement, there continues to be a lack of agreement regarding even basic terms. For example, bereavement, grief, and mourning are often used interchangeably. Further, there continues to be confusion regarding the proper term for grief or mourning that has gone awry, sometimes referred to as pathological grief, pathological mourning, or complicated grief.

In this monograph, basic terms of bereavement, grief, and mourning conform to definitions suggested by Margaret and Wolfgang Stroebe and Robert Hansson in *The Handbook of Bereavement*.¹ According to this convention, bereave-

ment is the objective situation of having lost someone significant; grief is the emotional response to one's loss; and mourning denotes the actions and manner of expressing grief, which often reflect the mourning practices of one's culture.

Several terms have been specifically defined for this monograph. Bereavement distress encompasses both uncomplicated and complicated grief, and has been divided into four levels: uncomplicated grief, uncomplicated grief with risk factors, complicated grief without clinical disorder, and complicated grief with clinical disorder. Uncomplicated grief is defined as the adequate management of the grief process in which the mourner successfully moves through the phases and tasks of mourning consistent with his or her own values and cultural norms. Complicated grief, on the other hand, includes an atypical intensity or duration of grief symptoms that leads to a level of functional impairment in critical areas of work and relationships. Again, it is important to emphasize that this approach presumes that bereavement even when characterized by uncomplicated grief and "the adequate management of the grief process" causes distress.

For several reasons, the monograph uses the term integrative to describe both the overall model of bereavement and the process of bereavement therapy. First, both the model and therapy are multidisciplinary in approach. Observations from anthropology, sociology, and philosophy are joined with psychological views of mourning and grief to broaden and strengthen the perspective. Second, the monograph makes great efforts to synthesize and integrate insights garnered from both empirical research and clinical practice into a coherent whole. Finally, efforts to integrate findings from both psychodynamic and cognitive approaches appear in all aspects of the model: the underlying view of grief and mourning, the differential diagnosis of levels of bereave-

ment distress, the selection of appropriate bereavement activities and interventions, and the application of these interventions.

Throughout the monograph, case materials illustrate theoretical and clinical principles. While based on actual clinical observations by the monograph authors or sources found in the literature most of these scenarios are amalgamations of several real-life examples, completely hypothetical cases, or actual examples that have been significantly altered to protect the confidentiality of clients. Furthermore, a noticeable bias toward case material with gay white men and their families reflects the clinical experience of the authors and the predominance of research and clinical writing in the field. To provide a more authentic picture of AIDS mourners, the monograph includes excerpts from three letters to the editor of *On Display*, the newsletter of the AIDS Memorial Quilt. These "true stories" provide additional insights from actual individuals and families coping with the loss of a loved one to AIDS. The names in these cases are real and the letters are used with the permission of the authors.

[2nd Subhead] Conclusion

Finally, as in so many other arenas of physical and psychosomatic medicine, the findings from research on and practice in AIDS bereavement has much to teach the broader field of bereavement support. Ideally, the model presented in this monograph will encourage other bereavement writers to combine historical, social, cultural, philosophical, and psychological perspectives into community and clinical approaches to assist other mourners. In the meantime, application of the principles presented here should serve clinicians well in their work with all mourners. If so in some small way this model will serve as a tribute to those who have died of AIDS and those who continue to work to help people with HIV and their loved ones. ■